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Title Page

Overcoming barriers to grief:
supporting bereaved people
with profound intellectual and multiple disabilities
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Abstract

Engaging people with profound intellectual and multiple disabilities (PIMD) in relation to issues of bereavement and loss may be seen as a complex therapeutic challenge. The author examines the barriers preventing them from engaging with therapeutic approaches and note that the extent to which the person engages with the grieving process partly depends upon how they are enabled to overcome these challenges. Through the lens of Worden's (2008) model, the author provides an assessment of the social, emotional and physical constraints that affect the person's experience of bereavement. Within this framework, suggestions and approaches for support are offered. This conceptual paper can be used to bridge the gap between theory and therapeutic practice, and provides the basis for future research involving this group.

Keywords: bereavement, profound intellectual and multiple disability, mental health, grief theories

Overcoming barriers to grief: supporting bereaved people with profound and multiple intellectual disabilities

Loss can be an incredibly painful, complex and confusing mix of experiences for someone with intellectual disabilities (ID) (Read, 2014). We may be increasingly more comfortable with having conversations around dying, death and bereavement more generally (Patterson et al, 2014), but are we getting any better at having those conversations with the most vulnerable people in society, including people with ID (Forrester-Jones, 2013; Wiese et al, 2013)? It is certainly the case that there is little recognition of the bereavement experiences of people with profound intellectual and multiple disabilities (PIMD) (Young et al, 2014a). Only several pieces of work, mainly in the UK and The Netherlands, have described some of those experiences and reactions to loss in this group. Moreover, in practice, bereavement counsellors may be perplexed by severe communication impairments, which present obvious therapeutic challenges (Clegg et al, 2003; Colman, 2003). Therefore, this paper is significant, to the researcher and practitioner, for how bereavement and healing is conceptualised in this group.

Why do people with PIMD present as a distinct group?

There are a variety of terms and definitions of PIMD within the international literature: ‘profound- ‘multiple/learning/intellectual disabilities’, ‘mental retardation’, ‘multiple handicaps’ (Nakken et al, 2002) and ‘mental subnormality’. Although terminology differs, there are some core elements to the ways in which ‘profound’ is defined. It is generally accepted that people with PIMD have the most severe cognitive impairments, with an IQ below 20 (Mansell, 2010). They are thought to be operating at a pre-verbal stage of development (Carnaby, 2004; Coupe O’Kane et al, 1998; Nind et al, 2001; Ware, 2003), which precludes the ability to act with intention, understand cause and effect, differentiate between subject and object and symbolically convey meaning. Overall, they are perceived as reflexive beings (Tang, Patterson & Kennedy, 2003), although this is extensively debated in ‘The PMLD Ambiguity’ (Simmons et al, 2014).

Against these proposed cognitive difficulties, many people with PIMD experience sensory impairments, (Kelleher et al, 1986; Evenhuis et al, 1998), epilepsy (Codling et al, 2008), respiratory problems (Wallis, 2008) and mobility limitations (Cleaver et al, 2009). Generally, they present as a distinct group in terms of the differences in their care needs and disabilities, which can be life-threatening (Pawlyn et al, 2008). More widely, these factors influence their ability to engage with their communities, live as active members of society, and express choice and control (Mansell, 2010).

What these definitions do not capture however, is the *profound* nature of people with PIMD as being a group which is difficult to know and understand with any great deal of certainty or insight. The Oxford Dictionary provides definitions of ‘profound’ as: “very great or intense”, “very deep” and “demanding deep study or thought” (Oxford Dictionary of English, 2015). Indeed, traditional approaches (e.g. cognitive psychology and behaviourism) have offered us very little light into their inner worlds and are restricted in their explanatory power of behaviour. Furthermore, these theoretical frameworks do not respect the profound mystery of this group. The argument here is that the nature of people with PIMD is not just specific to the individual’s cognitive limitations, but are also embedded within the wider experience of the world around them, and context-specific (Simmons et al, 2014).

Conceptualising bereavement in relation to people with profound intellectual and multiple disabilities

A theme that pervades the literature is the ongoing quest for the most suitable theory by which to understand bereavement and in those with ID. This search has always been complicated by the diversity of communicative abilities, which offer a wide variety of insights into their inner worlds. Research practitioners can be found acknowledging the ways in which responses to loss are expressed (Dodd et al, 2005) and seeking to identify a coherent framework within which to provide suggestions of support (Blackman, 2003; Read, 2014). In summary, applications of theory to the field have included task, phase and stage models of bereavement (see Read, 2014). Meeusen-van

de Kerkof et al (2006) is perhaps the first to explicitly apply theory to understanding bereavement in the profound group, and concentrates on cognitive development as a starting point from which to understand their experiences. This contribution will be explored further, but it seems potentially beneficial to strive for an encompassing conceptual model that might reveal a number of additional therapeutic approaches in this area. It is suggested that Worden's (2008) Four Tasks of Grief may be one such model to *facilitate* important considerations.

Conceptualising bereavement in people with profound intellectual and multiple disabilities

Worden's (2008) theory provides a complementary understanding of mourning; that the bereaved person, and those supporting them, can influence and change their experience of grief. He suggests that there are four tasks within the mourning process: to accept the reality of the loss, to process the pain of grief, to adjust to a world without the deceased and to find an enduring connection with the person. The use of Worden's (2008) theory, in the context of this conceptual paper, can be found in its ability to exemplify some of the tasks that we all engage with to some extent, but which may be complicated for people with ID and certainly for people in the profound group. Worden's (2008) theory assists us, perhaps paradoxically, to come closer to their bereavement experiences, as upon reflection of this theory we identify the many difficulties precluding engagement with the four tasks. Indeed, this challenges versus facilitation approach can be found in much of the literature relevant to this area (Luchterhand et al, 1998; Sormanti et al, 2011; Stoddart et al, 2002; Handley et al, 2013).

The aim of this paper is to utilise Worden's (2008) theory as a lens through which to examine bereavement experiences. It will suggest that a psychological, physical, social and spiritual analysis, in this respect, points to inclusive approaches which can overcome these barriers and respond sensitively. This is an important area of consideration, as this has not been previously studied in any great detail, in relation to this unique and often disenfranchised group.

Task One: Accepting the reality of the loss

Cognitive impairment – justification for exclusion?

For any of us to accept the reality of a loss, we must first come to know about that loss, but people with PIMD are often excluded from this. They make up part of the group for which death education is certainly considered inappropriate. It is argued that such people do not have the intellectual ability to understand complex concepts such as 'death' and 'dying' (Meeusen-van de Kerkof et al, 2006). Within this framework, people with PIMD are in the early phases of sensorimotor development (Piaget, 1954), a phase encompassing the concept of object and person permanence, but which is not, arguably, fully accomplished in this group. They claim that those things that are outside the realm of the senses do not exist to someone with PIMD. Lack of grief reactions are cited as support of this claim, although no strong empirical research is provided and a body of work is beginning to challenge this assumption (Phillip et al, 2005; Young et al, 2014a; Young et al, 2015).

This issue of cognitive impairment leads us to a further point that people with PIMD are perhaps the most disenfranchised group of the ID community, particularly in relation to mental health issues. This idea, developed by Doka (2002), highlights that grief can be disenfranchised when society does not recognise or accept that a person is experiencing loss and mourning. The few studies that have involved people with PIMD emphasise that we have not yet begun to include them as an integral part of the mental health literature and this has huge implications for practice (Sheehy & Nind, 2005).

Supporting Acceptance of the Reality of the Loss

Tuffrey-Wijne (2013) describes breaking bad news to people with ID as a process, which can begin long before the death of a loved one, loss or change. Similarly, in a framework of support, Read et al (2007b) emphasises the importance of education before participation, facilitation and intervention. Within this integrated framework, the authors suggest that these aspects be reflected in care delivery, from the level of the individual and family support through to organisational and national levels, with education serving the foundation for both the person and the carer. A case study is presented to illustrate the adverse effects of an approach that is counter to

this philosophy; Joan was not involved in her mother's funeral and subsequently experienced anger related to this exclusion. The authors highlight that had Joan's carers received adequate training they may have facilitated Joan's acceptance of the reality of the loss through inclusion in grieving rituals. This can be extended to include death education with people with ID themselves, and their families, which may also reduce risk of complicated grieving in the person.

Conversely, with the group of people with PIMD, Meeusen-van de Kerkof et al (2006) suggest that bereavement work should not focus on educating the person about death or dying, but instead provide concrete experiences of absence. Suggestions do not extend beyond supporting the person in response to changes in behaviour. However, the message of inclusion is strong: hospital visitations, attending funerals and visits to the grave can be incredibly significant places of meaning for the bereaved person and provide concrete experiences (Weeks, 2004). These events can provide experiences that help convey meaning. Of course, these are not the only opportunities that one has to experience loss, but they are arguably some of the most significant and memorable occasions, as they occur within a social setting with heightened emotions and reactions (Gaventa, 2014). A crucial point, because the innate capacities of intersubjective awareness (Trevarthen et al, 2001) do not preclude social referencing (the ability to read another and interpret their emotion) (Sorce et al, 1985).

Task Two: Process the pain of grief

Attachment experiences and affect regulation

Natural emotions related to grieving can be painful and difficult to experience. Worden (2008) highlights that 'being with' and accepting the emotions of grief can move the individual to a place where the emotions are better regulated and not causing overwhelming distress. A plethora of evidence supports the significance of early interactions with the caregiver as being the foundation for affect regulation (i.e. the ability to manage stress) (Schore, 2001). A review of this area reveals that cognitive difficulties, and neurological damage, may affect a person's ability to utilise attachment behaviours and relationships as a function for affect regulation (Janssen et al, 2002).

People with PMLD may therefore be more vulnerable to the effects of loss, lack the internal resources to manage related emotions and ability to obtain external support. Against this backdrop, we also know that attachment style can be associated with the experience and intensity of emotional pain related to loss (Bowlby, 1980). This has consequences for complicated grief if the person had or experienced, as may be the case in people with PIMD (Schuengel et al, 2009; Naber et al, 2007), an insecure attachment to the deceased (Parkes, 2006; Dodd et al, 2014).

What has yet to be explored is the impact of the many losses that people with PIMD and their family carers will experience, in addition to attachment relationships. For example, what is the impact of the profound disability itself in relation to trauma (Sinason, 1986) and experience of loss (Gaventa, 2014)? In addition, throughout their lives they will experience loss in stressful transitions from school to adult day services (McBride et al, 2012), death of their peers (Hogg et al, 2006) and paid-staff turnover (Buntix, 2008). Furthermore, many people with PIMD live with their parents, often into their parent's elderly years due to their increased healthcare needs. The concern around this arises when the parent dies and the person must navigate through the transition of losing one's parents, leaving home and moving to a new place to live (Oswin, 1991). In view of these factors, the psychosomatic problems associated with loss in this group (Phillip et al, 2005), and the difficulties in differentiating these from the rudimentary poor health, further complicates this picture. When there are many changes in one's life, it may be cognitively and emotionally difficult for the person to deal with the initial loss and can contribute to psychiatric disorder. This is exemplified in a case study of a young man with PIMD (Dosen, 2005), in which a number of adverse life events (including loss) led to changes in socio-emotional and cognitive functioning that preceded a psychiatric disorder.

Supporting the processing of pain related to loss

Understanding of these complex areas in relation to people with PIMD is lacking. The dearth of resources and training mean that people with PIMD rarely access appropriate support, and parents, carers and professionals feel unqualified to approach such a sensitive issue (Ng et al, 2003;

McEvoy et al, 2010). Due to the difficulties in communication, traditional forms of intervention such as counselling have not been an option (Dowling et al, 2006). Bereavement resources and training have only recently been developed for people with PIMD (Phillip et al, 2005; Young et al, 2014b), but there is much needed research and practice to evaluate their use.

It is clear from the attachment literature that emotions can be socially regulated. A sensitive and responsive caregiver is characterised by their ability to be mindful of the other person's experiences, thoughts and feelings and seeks to meet their needs (Gold, 2011). Indications as to whether support is healing may be indicated by deep breathing and emotional sounds when breathing out, e.g. groaning or grunting, indicating activation of the parasympathetic nervous system (Rothschild, 2000). Clamminess, rapid breathing, jerkiness and emotional sounds when breathing in, suggests activation of the sympathetic nervous system and may indicate the person's difficulty with the support provided (the applications of physiological measurements of emotion in people with PIMD can be explored in Vos et al's (2010) work). Research and practice are now exploring the potential value of attachment-based perspectives for understanding and alleviating the challenges that people with ID face in their mental health (Schuengel et al, 2009). One practical suggestion which may support regulation is rhythmic movement, drumming, music and massage as inherently regulating activities (Perry et al, 2008).

Task Three: Adjusting to a world without the deceased

Lacking choice and control

Death and loss can lead us to question the most basic assumptions that we make about predictability, security and safety. This may be particularly pertinent to people with PIMD, given the vulnerabilities they experience in relation to attachment relationships. The internal adjustments of which Worden (2008) describes, in order for healthy grieving, include assimilating to changes in relationships. The main barrier which may prevent people with PIMD from adapting to change is lack of choice and control. A study on happiness has suggested that those with PIMD have limited access to stimuli that is associated with happiness because of their difficulty in communicating their

preferences (Green et al, 1996). It was suggested that people with PIMD are particularly vulnerable to stress because of their inability to control their environment (Chaney, 1996; Phillip et al, 2005). Limited communication makes it difficult for the person to make known their wants and needs, and as such adjusting to a world without the deceased is challenging.

Supporting Adjustment

Although very painful, an expected death may be easier to deal with than an unexpected one, because more time will allow less abrupt change and adjustment (Tuffrey-Wijne, 2013). Anticipated death can also allow the person time to prepare for the death (Raphael, 1984). Identifying the changes in routine and how to move smoothly through these transitions will help to minimise stress and upset. Preserving a familiar day-to-day routine will help to maintain a sense of safety and predictability. Where appropriate the carer may use communication aids to facilitate the person's ability to make choices (Goldbart et al, 2010).

Task Four: Find an enduring connection with the person who has died

Mobility and communicative limitations

Worden (2008) emphasises the importance of continuing the relationship with the deceased in ways that are meaningful to the bereaved. Many people with PIMD experience a number of considerable mobility limitations (Cleaver et al, 2009). Those who do not have the physical ability to access sources of memories, such as photographs and videos, rely on others to facilitate this. They depend on sensitive others to do so, but this also involves that person identifying the most sensitive time to explore these, given that grief is thought to oscillate between loss and restoration tasks (Stroebe et al, 1999). Furthermore, our connections with people who have died are often relationally-based ones, facilitated by conversations and times of remembering the deceased with friends and family. Historically, the relationship narratives of people with ID have not been nurtured, meaning that their stories are often fragmented through loss and change (Atkinson et al, 1997). Difficulty communicating these narratives may make people with PIMD feel cut adrift, disconnected and misunderstood.

Supporting connections with the person who has died

In providing facilitation and intervention, it would be particularly beneficial for this group to engage with multi-sensory storytelling, creating artwork, memory boxes (Young et al 2011; Young et al, 2015) and life story work (Hewitt, 2000; Read et al, 2007a). For example, in a case study exploring the bereavement experience of a young woman with PIMD, Young et al (2015) demonstrated the use of a memory box as an important source of meaning around the loss. This supportive work as a means of fostering connection also concerns spirituality and ritual, which are not specific only to the task of enduring relationships, but are extremely relevant to connections that can be established at any point. The authors argue that the intellectual functioning of an individual is not an exclusive basis upon which to assess a person's ability, but that their spiritual experiences are also important (Meeusen-van de Kerkhof et al, 2013). Gaventa (2014) argues that each of us have a spiritual dimension and spiritual needs of people with PIMD must not be ignored (Swinton, 2002). For some people formal religion will be important. Religious rituals, stories and participation within an accepting community can be invaluable. For others, their spiritual needs might be met through their relationships, going to special places, encountering nature, music and art. All of these things can be important sources of meaning, hope, trust, value, identity and purpose. In fact, this is a crucial point upon which to end the main body of this text, for spirituality is an aspect that runs through all care and support with people with PIMD.

Discussion

It is argued that people with PIMD do not have the intellectual ability to understand complex concepts such as 'death' and 'dying'; that professionals lack the confidence, knowledge and skills required to explore these areas; and that a range of suitable resources do not exist to support such an exploration. Instead of including and supporting people with PIMD in the process of grieving, it is common for them to be excluded from this (Young et al, 2014a). Naturally, people with mild to moderate and severe ID may share some of the difficulties outlined in this paper. However, the severity of those difficulties, which characterise the group of people with PIMD, present unique

challenges, especially in relation to emotional and mental health issues. It is part of being human that we experience relationship *and* loss, but for people with PIMD, how much more difficult is this experience?

Worden's model as a lens

The present author suggests that cognitive approaches to the issue of bereavement in people with PIMD are restrictive in three ways. First, it neglects the significance of the person's historical narrative in relation to attachment relationships and what these have taught the person about love and loss, a subject which has been explored by Blackman (2003). Second, it abandons discussion around the important socio-cultural barriers which may prevent people with PIMD from engaging in the grieving process. Finally, from the claims that experience is dependant on intellectual disability, little is offered in terms of how we support bereaved people with profound cognitive impairments and communicative difficulties. While aspects of this framework has been subjected to a critical analysis, it nonetheless has highlighted an important element of bereavement and loss experience in people with PIMD that has been largely neglected. However, while the physical and cognitive impairments of people with PIMD are fixed, their experience of disability is not. In using Worden's (2008) model, it has diverted attention away from the impairment and has shifted focus on the barriers to the process of grieving, which have mainly arisen from lack of support and participation. One must not forget conversely, that although theories are valuable, we should continue to be guided by the bereaved individual.

Supporting parents and professional carers

Much of the literature on bereavement and people with ID has focussed primarily on the needs of the bereaved individual and very little attention has been given to the difficulties with which carers find providing support. Research has pointed to the challenges carers face in providing bereavement support: consent, confidence and guidance (Read, 2001; McHale et al, 2009). Moreover, training recommendations have included issues of complicated grieving and psychopathology (McHale et al, 2009; McEvoy et al, 2005). Recent research has highlighted the

emotional difficulty with which carers find exploring bereavement and loss issues with this group, particularly when they are grieving themselves (Handley et al, 2013). This is exacerbated by difficulties in understanding the grief reactions of people with intellectual disabilities, especially those that do not fit with expectations (e.g. delayed reactions, or not overt responses). Handley et al's (2013) study also reveals the importance of the carer having time to process the events before sharing news with the person. Carers may also be found remembering their own personal losses, which can affect their ability to explore these issues. Family carers and professional carers also articulate the uncertainty around offering bereavement support, when it leads to conflicting outcomes (i.e. for professional carers this involved intense support for one individual, disadvantaging others). The qualitative research strongly advocated for access to training for carers. The issues of staff confidence and knowledge is one that presents itself as a further barrier to grieving for the bereaved person and must be sensitively addressed.

Future Research

One must question the extent to which our current research and understanding has been affected by the barriers outlined in this conceptual paper. In other words, how can we fully understand the experience of bereavement in this group if we have not enabled them to engage with such an experience? Future research in this area is therefore warranted. It would also be interesting to evaluate the suggestions of support with empirical research. It is perhaps the case that the lack of research in this area has impeded practice and support for this group.

Overall, considerations of the bereavement experiences of people with PIMD require interpretation. It would be important to critically assess whether the cognitive approach is sufficient to describe their experiences. How much more difficult is it for people with PIMD to understand loss and what do their grief reactions tell us about their understanding? Furthermore, the question of whether bereavement research in mild to moderate and severe ID is applicable to people with PIMD is a crucial one. Research is yet to establish this.

Conclusions

The author has provided an assessment of the social, emotional and physical constraints that affect the extent to which people with PIMD engage with the tasks of grief, outlined by Worden (2008). These constraints range from barriers that are related to the views held by society, to barriers that are inherent in the disability of the individual. Suggestions of support include effective communication, listening and responding to upset and distress, providing opportunities to remember the person and encourage ways of maintaining the emotional bond with the deceased. In conclusion, bereavement support for people with PIMD benefits from consideration of socio-cultural barriers. While we cannot take the pain of the loss away, we can help to alleviate some of the barriers which prevent people with PIMD from grieving in supported ways.

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